



## Raising Cane

Rob Perez

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# Family duties jeopardize caregiver's future

### The basic documents

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Seven years ago Tamiko Onodera, grieving over her 80-year-old mother's abrupt death, suddenly became the only caregiver for her 85-year-old father, a stroke victim who was paralyzed and needed constant care.

Onodera also was executor for his estate, which at the time included the elderly couple's \$425,000 Pacific Heights home and investments worth close to \$200,000.

Onodera, who has a master's degree in fine arts, wasn't prepared to serve either role.

Yet she did so diligently and dutifully, caring for the retired architect and overseeing his financial and legal affairs until he died in 1998.

Today, five years after Kenji Onodera's death, Tamiko Onodera, 61, still is struggling to deal with lingering issues from the decade she spent helping her mother care for her father and, following her mother's death,

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the two years she was responsible for her father's well-being.

Today, Onodera is broke, jobless and in search of a home.



COURTESY PHOTO

Tamiko Onodera is here with her father, Kenji Onodera, in 1997, about a year before his death. Seven years ago when her mother died, Tamiko suddenly became the only caregiver for Kenji until his death. Today, Tamiko is broke, jobless and in search of a home, her situation caused in part by lingering issues related to more than a decade spent caring for her father.

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She is estranged from her only sibling, a brother living in California, partly over disagreements they had following their parents' deaths. The disagreements focused largely on how to deal with their parents' assets -- a common topic of dispute among siblings following the death of the last

surviving parent.

Onodera's relationships with other relatives, also living on the mainland, have suffered as well.

"It's hard for someone who hasn't gone through this process to imagine how much of a toll caring for an elderly parent takes out of you," Onodera said. "It's very emotionally draining."

Onodera shared her story with me in part to raise awareness of issues related to adult children caring for elderly parents.

Like others who have had similar experiences, Onodera says caregivers often are so focused on -- yet ill prepared to handle -- the enormous task at hand that they tend to overlook their own needs. A lack of sufficient government and community support services makes the task all the more difficult, Onodera and other caregivers say.

Yet as our population ages, many local families eventually will find themselves facing the same issues, the same challenges.

More than 100,000 people in Hawaii already provide informal care, according to industry estimates, and the number is expected to continue growing. The care can be as simple as driving a parent to doctor's appointments to feeding, bathing and providing other services on a continuous basis.

A state-sponsored survey of nearly 450 unpaid caregivers last year found that the average age was 60, and the vast majority, 81 percent, were female.

The majority of respondents said they had adjusted well to their caregiving duties, citing the importance of family support.

More than a quarter, however, said they were depressed. And those who lived with their care recipients were more likely to report they were unhappy and financially struggling.

Onodera said she was fortunate that her parents had saved enough money to cover their needs in their final years.

But when Onodera interrupted her career as a manufacturer's sales representative in the mid-80s to help care for her father, she made the mistake of not getting anything in writing from her parents to stipulate how she would be compensated. She simply was acting out of a sense of familial obligation.

Experts who deal with the elderly say family caregivers often don't get anything in writing because they trust everything will work out.

But when the last surviving parent eventually dies and the siblings try to settle the parent's estate, a lack of written agreements can lead to bitter disputes.

"We see this quite often," said James Pietsch, a University of Hawaii law professor and director of the UH Elder Law Program.

"Caregiving can be a very volatile issue" because of sibling disagreements, agreed Karen Miyake, the county's executive on aging. Her office has a seniors hotline (523-4545) that caregivers can call with questions.

Because Onodera didn't have a written agreement stating that her living expenses would be covered by her father while she cared for him, she ended up paying thousands of dollars to her brother once their father's estate was settled.

The tab covered expenses such as her physician visits, food, auto insurance, a \$100,000 remodeling project at her father's residence and other expenses she assumed the estate would cover.

Given that she was solely responsible for her father's well-being, Onodera tried a number of arrangements to lighten her burden and prevent burn-out -- a common problem with caregivers who have little or no help.

For a few months, she placed her father in an assisted-living home, but that got too expensive, and Onodera wasn't satisfied with the quality of care.

She then struck a deal with a graduate student and his wife. Their room and board at the Onodera home would be covered in exchange for helping with her father.

It was arduous and constant work: Changing his clothes and diapers, bathing him, helping him move around the house, taking him to appointments.

After her father died, it took several years for Onodera and her brother to settle their father's estate, partly because of their disagreements.

Onodera also had trouble getting her life back in order.

She sold the Pacific Heights home in early 2002 to stave off a foreclosure. That left her with no home, some savings and little else.

And she had difficulty finding work. Employers weren't interested in hiring a woman approaching retirement age who had left her full-time career nearly 20 years earlier.

"It's very, very difficult to pop back and just get back to work," Onodera said. "I was in denial about how bad my situation was."

She tried her hand at selling real estate, but that didn't pan out.

Onodera eventually spent a big chunk of her savings on a risky property deal on the Big Island, with visions of establishing a successful bed-and-breakfast business. That also didn't pan out.

With few options and a depleted savings account, she's now applying for basic retail and secretarial jobs.

Onodera said she has talked to other caregivers who

interrupted their careers for years and are now having trouble returning to the work force at the same level as before. One woman with a doctorate degree told Onodera she is working as a sales clerk.

"Everywhere I go I hear stories like this," Onodera said.

Those are stories that should have happier endings.

And if Onodera's experience teaches us nothing else, it's that written agreements covering caregivers can help keep their tales from turning into unexpected tragedies.

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## **The basic documents**

Planning ahead can prevent family squabbles and unnecessary costs when an elderly parent becomes incapacitated and needs care. Here are documents that will help:

>> Power of attorney, provided to the person who handles the finances and legal affairs for the parent.

>> Advanced health care directive, to state the parent's wishes if he or she becomes terminally ill or lapses into a coma. It also designates the person who will make health-care decisions if the parent is unable to communicate with the physician.

>> A will (70 percent of Hawaii residents don't have one).

>> A revocable living trust, which ensures the parent's assets won't be tied up in probate court upon his or her death.

>> An agreement stating how a family caregiver, if there is one, will be compensated.

Source: David Larsen, attorney and author

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